EMBRYO DONATION FAMILIES: MOTHERS' DECISIONS REGARDING DISCLOSURE OF DONOR CONCEPTION

Abstract

BACKGROUND: Findings are presented of a study of families with a child conceived using donated embryos. This paper focuses on the patterns of disclosure of the method of conception from mothers to children and other family members. METHODS: A total of 21 embryo donation families with a child aged 2-5 years were recruited through UK fertility clinics. Mothers were administered a standardized semi-structured interview, obtaining data on the extent of their disclosure to others and their reasons for this decision. RESULTS: Less than 10% of mothers had told their child how they were conceived at this stage, with 24% of mothers reporting that they were planning to tell the child in the future. However, nearly three-quarters of mothers had disclosed to other family members. Reasons cited for non-disclosure to the child included the desire to protect the child, the belief that disclosure is unnecessary, and the concern that family relationships would be damaged. Reasons in favour of disclosure included the desire to avoid accidental disclosure and the belief that the child has a right to know. CONCLUSIONS: Embryo donation mothers resemble parents of donor insemination and oocyte donation children in their attitudes towards disclosure of donor conception.

Introduction

Embryo donation is an assisted reproduction procedure that can be utilised either when both members of a couple are found to be infertile, or when previous IVF or ICSI treatments using the couples' own gametes have been unsuccessful (Trounson et al., 1983). In the UK, embryo donation is still relatively uncommon compared to other forms of assisted reproduction, with an average of around 35 children conceived in

this way born each year over the last decade, compared to ~800 by sperm donation and ~400 by oocyte donation (HFEA, personal communication). This is partly due to couples' desire to use their own gametes where possible, and also to the scarcity of available donated embryos. The majority of donor embryos used in treatments in the UK had originally been created by another couple in their own IVF cycles. Thus, the recipient couple will raise a child that is genetically related to the donor couple and who may have full genetic siblings elsewhere; a situation that structurally parallels adoption. Nevertheless, embryo donation parents differ from adoptive parents in that the recipient mother is also the gestational mother.

One significant consequence of this gestational relationship in embryo donation families is that it allows parents a choice about whether or not to disclose the non-genetic relationship to others and to the child. The issue of disclosure of the method of conception in families with children conceived using donor gametes has been the centre of extensive debate (Daniels and Taylor, 1993; Shenfield and Steele, 1997; McGee et al., 2001; Patrizio et al., 2001). Historically, secrecy was the accepted position in gamete donation, with clinicians typically advising couples that no one else need know (Mahlstedt and Greenfeld, 1989). Over the last two decades concern has grown about the possible adverse effects of this secrecy, particularly with regard to family relationships and the psychological well-being of the child. The result has been a worldwide change in climate towards encouraging disclosure, reflected in the implementation in the UK of legislation ending the previous practice of anonymous donation and allowing donor offspring conceived since April 2005 (although not those conceived prior to this) access to the identity of the donors on reaching age 18.

The disclosure debate has involved international experts from the fields of mental health and social work, as well as assisted reproduction clinicians, patients,

and donor offspring (e.g., Daniels and Taylor, 1993; McWhinnie, 2001; Shenfield and Steele, 1997; Walker and Broderick, 1999). Those in favour of openness draw parallels between donor conception and adoption. There is an emphasis in the adoption literature on the importance of knowing one's genetic origins, and that not being given this information may have a detrimental effect, particularly on identity development (Triseliotis, 1973; Howe and Feast, 2000). Part of the process of establishing a coherent sense of identity for non-adopted individuals involves incorporating knowledge about their past and their family into their sense of self (Erikson, 1968). An adoptee lacks this geneaological continuity and so may find difficulty in developing a secure and healthy sense of ego identity, possibly resulting in insecurity and emotional problems. However, evidence suggests that adopted children deal better with this issue when there is open communication about adoption in the family (Brodzinsky et al., 1998). In the same way, it is argued that donor offspring may suffer similar harm to their emotional and identity development if they lack knowledge about their genetic background, and would benefit from open discussion (Snowden et al., 1983; Baran and Pannor, 1993; Daniels and Taylor, 1993). However, donor conception families differ from adoptive families in that the child has not been relinquished by existing parents, the child has a biological link to the mother through gestation, and the father has been present throughout the process. Thus, the challenge of forming a coherent identity faced by adoptees will not necessarily be encountered by donor offspring.

Another source of endorsement for openness draws on family therapy work. Studies suggest that the deception involved in secrecy can adversely affect honest communication and relationships between parents and children (Clamar, 1989). Children may become aware that their parents are keeping information on certain

topics from them, which could provoke anxiety and confusion and possibly lead to the development of emotional problems (Papp, 1993). Moreover, if other family members are aware of the donor conception, there exists a distinct possibility that the child could find out from someone else. Such accidental disclosure may break the bonds of trust between parents and children, and is suggested to be more harmful than planned disclosure during early childhood (McWhinnie, 2001). Some support for this comes from a study by Turner and Coyle (2000) of offspring who learnt of their donor conception in adolescence or adulthood and reported consequent negative feelings about their parents, although the participants were recruited from support groups so are not necessarily representative of all donor offspring.

Further support for sharing information about the donor conception with the child is based on human rights arguments (Gollancz, 2001). Non-disclosure is claimed to be against a child's right to autonomy and to information about their person (McGee et al., 2001). Legally, Article 8 of the 1950 European Convention on Human Rights guarantees the right to 'respect for private and family life'. It has been argued, e.g. in Blyth (2002), that knowledge about genetic origins is an essential element of private life, and that the child's right to this information should be the paramount consideration.

In contrast, those who defend non-disclosure to donor conception offspring argue that competing with the child's 'right to know' is a right of the parents to privacy and to make autonomous decisions about issues that may affect the welfare of the child (Shenfield and Steele, 1997; Walker and Broderick, 1999). To enforce disclosure would be to confer lower standards of rights to privacy and liberty to infertile couples than to fertile couples (Patrizio et al., 2001). From this perspective, parents have the prerogative to opt to keep the information private. It has also been

suggested that disclosure of the donor conception to the child could damage the relationship between the child and the non-genetic parent(s), with negative consequences for the child's emotional development (Snowden and Mitchell, 1981). Furthermore, it is argued that there still exists social stigma surrounding infertility and the use of donor gametes. Privacy about the conception allows both the child and couple to be protected from any negative societal attitudes, and prevents the family from being treated differently (Nachtigall et al., 1997). The notion that disclosure is not essential is supported by research showing that adolescents conceived by gamete donation who are unaware of their conception do not exhibit increased levels of emotional difficulties or dysfunctional relationships with their parents as compared to control groups of naturally conceived adolescents (Golombok et al., 2002; Murray, MacCallum, and Golombok, 2006). However, problems may still emerge as these offspring enter adulthood.

Turning from the academic debate to empirical research, early studies of gamete donation parents found that the majority tended not to disclose the donor conception to the child. In a review of studies published between 1980 and 1995 of donor insemination families, Brewaeys (2001) found that few parents (between 1% and 20%) intended to tell their child about their genetic origins. The European Study of Assisted Reproduction Families, conducted in Spain, the Netherlands, Italy and the UK, found that less than 10% of donor insemination parents had told their child about their conception by early adolescence (Golombok et al., 2002). A study of UK oocyte donation families by Murray and Golombok (2003) found slightly higher disclosure rates, but still only 29% of couples stated that they were definitely planning to tell their child. In contrast, adoptive parents as a rule begin to explain the circumstances of the adoption to the child from a young age (Brodzinsky and Pinderhughes, 2002).

However, more recent research on gamete donation families in the UK with children conceived from 1999 onwards, has found some evidence that attitudes are changing. When the children were aged 9-12 months, 46% of donor insemination parents and 56% of oocyte donation parents stated that they intended to tell, demonstrating a marked increase (Golombok et al., 2004). Nonetheless, it remains to be seen whether the parents will carry through this intention as the children grow up.

Research assessing why gamete donation parents decide not to tell the child has found consistent patterns. One reason frequently cited by both donor insemination and oocyte donation parents is to protect the child either from the distress of discovering that he/she is not genetically related to one parent, or from the upset caused by not being able to discover any information about the donor (Nachtigall et al., 1997; Lindblad et al., 2000; Murray and Golombok, 2003). Another common reason for non-disclosure is the protection of the non-genetic parent and their relationship with the child (Cook et al., 1995; Murray and Golombok, 2003). Many donor insemination parents also report that disclosure is unnecessary, since the non-genetic parent is the one who has raised the child (Lindblad et al., 2000), and in the case of oocyte donation, the parents point out that the mother has carried and given birth to the child (Murray and Golombok, 2003). Thus, non-disclosing parents often highlight the social and gestational relationships between parent and child as being more relevant and important to parenthood than the genetic relationships.

So far there has been little research focusing specifically on embryo donation families and their decisions regarding disclosure. Soderstrom-Antilla and colleagues (2001) interviewed 27 couples in Finland who had been treated with donor embryos and found that 69% of them thought that a child conceived in this way should be informed about the manner of their conception. However, only 11 of these couples

(41%) had actually had a child at the time of study, only 5 of these had definitely decided to inform the child, and it is not reported how old the children were or whether disclosure had already taken place. Therefore, questions remain as to whether parents in embryo donation families will tend towards the adoption model of full disclosure, or will resemble more closely other donor conception families in keeping the method of conception relatively private.

To address these issues, the present study examined the disclosure patterns of a group of embryo donation mothers from the UK with a child aged between 2 and 5 years, asking whether they had told their child and their family about the use of donor embryos. Mothers' reasons for their decisions were explored in order to look at the thinking processes behind opting for disclosure or non-disclosure.

Materials and Methods

Participants

Twenty-one families with a child conceived using donated embryos were recruited through three UK fertility clinics. All two-parent heterosexual couples with an embryo donation child aged between 2 and 5 years inclusive at the time of study at each of the participating clinics were asked to take part. Children born at less than 30 weeks gestation were excluded, as were those with severe congenital abnormalities. To maintain confidentiality, parents were approached in the first instance by a letter from the clinic's Medical Director. The study was approved by the Ethics Committee at City University, where the research team was based. Thirty-seven families were contacted and 29 families replied (8 declined to participate), giving a response rate of 72% of those whom it was possible to trace (since the couples had been treated up to 5 years prior to the study, some had since moved house). Due to confidentiality regulations, no further information was available on those families who refused to

take part. Fifteen of the participating families had children born from singleton births, and six families had twins. Findings from this sample relating to quality of parenting, parental psychological state, and child development have been reported elsewhere (MacCallum et al., 2007).

There were 13 boys and 8 girls in the group, with the mean age of the children being 3 years and 6 months, and the mean age of the mothers being 43 years. Twenty of the families had two co-habiting parents, and one couple had separated since the birth of the target child. All couples had conceived using anonymously donated embryos (i.e. prior to the UK legislation change in April 2005).

Measures

A researcher trained in the study techniques visited each family at home. Parental attitudes towards disclosure of the use of donated embryos were assessed using semi-structured interviews administered to mothers and fathers separately (data from fathers and inter-couple comparisons will be reported in a future article). The following information was obtained from mothers: 1) whether or not they had told or planned to tell the child about the method of conception; 2) their reasons for this decision; 3) the extent of mothers' disclosure to family about the child's donor origins; and 4) their reasons for disclosure or non-disclosure to family. Interviews were tape-recorded (with mothers' permission) and transcribed verbatim.

Information from the interviews were analysed in two ways. Firstly, data relating to the extent of secrecy, and the reasons given for disclosure or non-disclosure were coded into pre-set categories, according to strict coding criteria derived from previous theory and investigations of disclosure in gamete donation families (e.g. Cook et al., 1995). For those mothers who did not intend to share this information with their child, their reasons for this decision were classified into the

following variables, each of which was rated as 'yes' or 'no': 1) to protect the child; 2) to protect family relationships; 3) no need to tell; and 4) don't know what/how to tell. Data from those mothers who had told their child, or planned to tell them in the future were coded thus: 1) the child has a right to know; 2) to avoid accidental disclosure; and 3) no reason not to. With respect to disclosure to family members, the responses of mothers who had not told their family were rated according to the following categories: 1) to protect the child; 2) to protect the mother; 3) to protect the father; 4) to avoid disapproval; and 5) no need to tell. Similarly, the responses of mothers who had told their family were classified thus: 1) wanted to share; 2) no reason not to tell; 3) to avoid accidental disclosure; and 4) had to tell/no choice. Mothers were not constrained to giving a single response, but had the opportunity to describe all the reasons influencing their disclosure decision. Where more than one reason was reported, each of these was rated, e.g., if a mother who had not disclosed to her family mentioned wanting to protect the child and wanting to avoid disapproval, both of these categories were coded as 'yes'.

Secondly, the transcripts were content analysed according to the themes defined by the quantitative variables above. The NVIVO statistical software package was used to assist in the exploration and coding of the transcribed texts (Gibbs, 2002). This method was adopted to obtain more in-depth information about the specific issues encompassed by the response categories, e.g. if a mother mentioned a desire to protect the child, the transcript was examined to establish what she was trying to protect him/her from.

Results

Extent of Disclosure

Disclosure to child

Of the 21 embryo donation mothers, only 9% (n = 2) had already told the child about the method of conception. A further 24% (n = 5) reported that they were planning to tell the child in the future. Forty-three per cent (n = 9) had definitely decided that they would never tell the child, and the remaining 24% (n = 5) were undecided.

Disclosure to family

Seventy-two per cent of the embryo donation parents (n = 15) had told at least one family member about the donor conception, leaving 28% (n = 6) who had not told any of their family. Maternal grandparents were significantly more likely to have been told about the method of the child's conception than were paternal grandparents (n = 11 vs. n = 9; 53% vs. 43%; $\chi^2 = 7.47$, $p < .025$).

Reasons for disclosure/non-disclosure to child

For the purposes of examining parents' reasons for disclosure or non-disclosure to the child, the families were divided into 2 groups. The first group included all parents who were inclined towards non-disclosure, and comprised those mothers who had definitely decided not to tell and those who were undecided (n = 14; 67%). The second group included all mothers who were inclined towards disclosure, and comprised those who had already told their child and those who stated an intention to tell when the child grew older (n = 7; 33%). This approach follows that of previous studies (Brewaeys et al., 1997; Lycett et al., 2004) where those who had already told formed a composite group with those who were intending to tell.

Non-disclosure to the child

To protect child. Sixty-four per cent of the non-disclosing mothers (n = 9) reported a desire to protect the child from the possible negative consequences of disclosure. From the content analysis, two separate concerns emerged. Firstly, the most frequently identified issue was a fear that the child would be upset or confused on

learning that his/her parents were not genetically related to him/her, as illustrated by this quote:

"I think it would cause a lot of insecurity with [child] really and a lot upheaval, a lot of upset…"

The second factor in protecting the child stemmed from the practice of clinics using anonymous donors. Mothers felt that the lack of genetic information available would make disclosure more distressing than beneficial to the child:

"He's not going to be able to find out so why make him think Daddy and I weren't his real parents?"

"The people that actually donated embryos wanted their anonymity, and if you start telling children…, they could quite easily go in search of trying to find out who the real parents are, the biological parents, which could be very upsetting for them."

To protect relationships with family members. Forty-three per cent of the non-disclosing mothers (n = 6) expressed a concern that family relationships, particularly parent-child relationships, would be damaged by disclosure. They feared that the child may reject them on learning of the absence of a genetic link. As one woman stated:

"Possibly you'd get the 'you're not really my parents', you know, 'what right have you got?'"

Mothers were also concerned that the child would feel isolated from the rest of the family if they were aware that they were not genetically related:

"I don't want him to feel left out, I want him to know he's got a family that will look after him, …I want him in with sort of like the family rather than outside"

No need to tell. In addition, forty-three per cent (n = 6) of the non-disclosing mothers were rated as feeling there was simply no need for disclosure. The most common

justification given was that since the mother had carried the child in pregnancy and given birth, she is to all intents and purposes the 'real mother'.

"You're going to be carrying them for 9 months, you're going to be feeding them for 9 months, to all intents and purposes, you are their mummy."

Similarly, since both the mother and father have been the nurturing parents from the beginning of the child's life, the fact that they are not the genetic parents is irrelevant.

"We've brought them up, so it's not an issue that's important really. The important thing is that… they've got a mum and dad who loves them and the actual genetics is a by-the-by."

Don't know what to tell. Only one mother specifically stated that she and her husband were inclined towards non-disclosure due to uncertainty over how to tell their child:

"It would be very difficult to explain, it's complex, it's hard for adults to understand, so how would he understand?"

Disclosure to the child

To avoid accidental disclosure. The most common reason, given by five of the seven mothers (71%) who were inclined towards disclosure, was a fear that otherwise the child may accidentally discover the facts later and find this difficult to cope with. This was particularly prevalent when other people had been told, for example:

"[Husband's] family knows about the treatment, my family know about the treatment, so in effect it could be an innocent comment one day that was said to [child] and then he's going to have the option to turn to me and say 'but you didn't tell me'."

Right to know. Over half of the disclosing mothers (57%, n = 4) stated that the child had a right to know the truth. In-depth analysis of the transcripts found that responses in this coding category could be further divided into two sub-categories. Some felt

that the information was part of the child's life story, particularly from a medical perspective:

"If they had a medical problem that wasn't hereditary from us but could be hereditary from the donors, they might question as to why. And I feel they should know in advance."

For other mothers, the feeling was more that children generally have a right to honesty from their parents, including the information about their genetic backgrounds.

"I do believe in being honest, no matter how much you don't like the truth, it's always best to be upfront."

No reason not to tell. Two of the disclosing mothers reported that there was simply no reason not to tell the child, since they felt the treatment was nothing to be ashamed of:

"I don't see why it should be a secret, I wouldn't think of it as anything to be concerned about."

Reasons for disclosure/non-disclosure to family

The reasons for non-disclosure were analysed for the six mothers who had told no family members, including the maternal grandparents, about the donor conception.

Non-disclosure to family

To protect the child. Three of the 6 non-disclosing mothers (50%) had not told the family in order to protect their child. Analysis of the transcripts revealed that these women were concerned that the family would treat the child differently if they knew that there was no genetic relationship, as the following quote demonstrates:

"As far as my family are concerned…, we've just had a little boy and he's still family…, he hasn't been bought into the family as an outsider."

To avoid disapproval. Three of the mothers (50%) were concerned that the family, particularly the grandparents, would react negatively to the use of donor conception.

The feeling seemed to be that since the grandparents were older, and as one mother put it, "of a different generation", they would not understand or approve.

"You see my mum's 83 and she's a very very devout Catholic. And she would not understand. And for her to find out now, it would do her more harm than good…, it would upset her immensely."

Other reasons. Two mothers (33%) had not fully disclosed to their family due to the husband's wish to keep *his* infertility secret. In both cases, the families were aware that the couple had undergone IVF treatment but not that donor embryos were involved, although one woman did tell her family that she was using donor oocytes:

"I didn't want [husband] to feel that, because his sperm is no good, I didn't want it to reflect on him…, I didn't want the family to sort of be 'Oh he's no good, he can't produce any children'…, so I just said it was my fault…, so we done donated eggs but you know the sperm is [husband's]."

In addition, two mothers (33%) strongly felt that the donor conception was a private matter between the couple, and not something to be discussed with anyone:

"It's something that's very personal and private, you know it's the less people know really, isn't it? You know, it's something that's keeping within a very close circle."

Disclosure to family

The reasons given for discussing the child's origins with the family were assessed for the remaining 15 mothers..

Wanted to share. The most common reason for disclosure to the family was simply that the mother wanted to share this information with them, cited by 87 % (n = 13). These women said that they generally discussed most personal matters with their families, and therefore did not see why this issue should not also be discussed.

"I think it's just that we've got quite a close relationship with both sets [of parents] really that it seemed to be a big thing not to tell."

To avoid disclosure. Twenty percent of the mothers (n = 3) had told their family because they were concerned that they would find out from another source:

"Can't really keep secrets, can you? They always come out of the woodwork somehow, people always find out the truth, I don't know how they do it, but they do."

No reason not to tell. Twenty percent of mothers (n = 3) responded that there was no reason not to tell their family, since they did not feel it necessary to keep the method of conception secret, and they preferred to be honest with family members:

"I don't really know, just couldn't see any reason not to tell them really…, I've always thought it's important to be truthful."

Other reasons. Two women gave other reasons for telling their families about the donor conception. One mother felt that she had no choice but to disclose, since the families were already aware of her fertility problems:

"Because everyone knew I couldn't have children anyway so…"

For the other mother, disclosure to the family was related to her intention to disclose to her children. She felt therefore it would be easier for "if they knew that Grandma knew, and still loved them for themselves and not for 'what they are'."

Discussion

The findings demonstrate that embryo donation parents do not follow the full disclosure model of adoptive families, with the large majority of embryo donation mothers deciding not to tell the child about the method of conception. Only one-third of mothers had told or were planning to tell the child, and just under half reported that they had definitely decided against telling. In contrast, most had disclosed the facts of the donor conception to someone else, with 72% having told at least one family

member. In this respect, embryo donation parents resemble earlier studies of gamete donation parents with children born before 1995 (Brewaeys, 2001; Murray and Golombok, 2003). However, a recent study of donor conception parents with infants conceived between 1999 and 2001 found that almost half of donor insemination parents and more than half of oocyte donation parents were planning to disclose (Golombok et al., 2004). This implies that, unlike other gamete donation parents, the attitudes of embryo donation parents may not be changing in line with the prevailing attitudes towards openness, and that they may be particularly private about this issue.

The proportion of embryo donation mothers in the current study who were inclined towards disclosure is much smaller than the 69% of embryo donation recipients in a Finnish sample (Soderstrom-Antilla et al., 2001) who reported that they believed children should be told about the method of their conception. The less open attitudes seen in the UK sample may reflect cultural differences. Although there was no explicit legislation regarding assisted reproduction in place in Finland when the research was conducted, the fundamental principle guiding the use of such treatments is the protection of the rights and interests of the child (Burrell, 2005). It is possible that this emphasis has engendered more positive attitudes towards disclosure in Finland than are seen in the UK, where the rights of the parents are considered to be of equal importance. However, it is important to note that not all of the Finnish couples had actually had children, and of those who had, more than half had not disclosed to their child. Couples' reported intentions regarding disclosure are not always reflected in their future behaviours (Golombok et al., 2002), so in practice the Finnish sample and the mothers in the current UK study may not be so different.

When the reasons for non-disclosure to the child were examined, the most common rationale was that disclosure could be more harmful than beneficial to the

child, either because learning that he/she is genetically unrelated to both parents would be disturbing in itself, or because donor anonymity would cause frustration if the child wished to trace the donors. The same reasoning has been consistently given previously by non-disclosing gamete donation parents. (Nachtigall et al., 1997; Lindblad et al., 2000; Murray and Golombok, 2003). It may be especially salient in embryo donation where there is no information on the genetic background, whereas in other gamete donation families half of the child's genetic heritage is known.

Another frequently stated reason for non-disclosure was anxiety that knowledge about the donor conception would adversely affect family relationships, particularly between parents and children. Protection of the non-genetic parent's relationship with the child has been used as an explanation for non-disclosure in previous studies of gamete donation parents (Cook et al., 1995; Murray and Golombok, 2003). With embryo donation, *both* parents lack a genetic link resulting in the fear that disclosure would lead to *both* parents being rejected by the child. Again, the complete absence of a genetic relationship between the parents and the child seems to be contributing to the comparatively high rate of non-disclosure in embryo donation families.

Donor insemination parents have often reported that disclosure is not needed because the social relationship between father and child is more relevant than the biological relationship (Golombok, et al., 2004; Lindblad et al., 2000). Oocyte donation parents have additionally justified their non-disclosure on the basis that the mother is the biological parent through gestation (Murray and Golombok, 2003). The embryo donation mothers cited both of these factors as rendering disclosure unnecessary. Assisted reproduction techniques allow the separation of different aspects of parenthood that usually co-occur, i.e. genetic, gestational and social

contributions. Non-disclosing embryo donation parents tended to emphasise the social and gestational components as more vital to parenting than the genetic.

In part, the reasons given for non-disclosure by embryo donation mothers reflect differences between embryo donation and adoption. For some couples, the decision not to disclose arose from the experience of pregnancy and birth and the presence of the father throughout the process, which does not occur in adoption. Moreover, unlike adoptive parents, embryo donation parents have no information to give the child about their genetic heritage. From this perspective, it has been suggested that anonymity of donors supports non-disclosure (Daniels and Taylor, 1993). Conversely, it has been argued that parents might feel that donors would present a greater threat to family cohesion if they were identifiable, and therefore disclosure would be less likely (Pennings, 1997). Studies of UK donor conception families with children conceived after the implementation of the donor identity legislation would help in establishing which of these influences were at work.

Considering the few embryo donation mothers who had decided to disclose to the child, over half agreed with the argument propounded by many professionals working in the area of assisted reproduction that the child has a right to know his or her origins (Daniels, 1995; Blyth, 2002). Moreover, two mothers felt that there was no reason not to tell the child, since there was no shame in conceiving in this way. However, the reason most often cited was that parents wished to avoid disclosure from someone else. All three of these explanations, in particular the child's right to know and the desire to avoid disclosure by others, have been previously found to be common reasons for disclosure in gamete donation families (Golombok et al., 2004)

This concern regarding accidental disclosure may be justified since 72% of parents had disclosed to family members, a proportion comparable to or higher than

that found in previous studies of donor conception families, For example, in Murray and Golombok's (2003) study, 65% of oocyte donation couples had told a family member, and in Brewaey's (2001) review of studies of donor insemination families, approximately 50% of all couples had disclosed to someone in the family, although many regretted this openness once the child was born. Similarly, in a study by Klock and Greenfeld (2004) of disclosure by oocyte donation couples, although 82% of women and 66% of men reported telling others, the majority of couples regretted this disclosure and stated that if they were to do it again, they would not tell. It is possible that couples are willing to disclose to others during treatment, but that their attitudes change after the birth when the information becomes more salient. If views on disclosure alter once the child is born, this could explain why, of those who had told family members in the present study, only 47% were also planning to tell the child.

In contrast, just over one quarter of the couples had told no one about the embryo donation. These parents were concerned that the family would ostracize the child or would show overt disapproval of the treatment, implying that they perceived some stigma associated with the method of conception or with their infertility. Previous research suggests that women may be more comfortable disclosing oocyte donation than men are disclosing donor insemination, either because there is more shame attached to male infertility (Daniels and Taylor, 1993), or because the mother's gestational relationship makes the lack of genetic link less important (Greenfeld et al., 1998). This was true for two mothers in this study, who felt that it was acceptable to tell the family about their own infertility but not that of their husbands.

The major methodological limitation of this study is the small size of the sample. To some extent, this was unavoidable since embryo donation treatment is infrequent in the UK. The participating clinics were in different areas of the country,

ensuring that the families were dispersed across regions in an attempt to recruit as representative a sample as possible, and the response rate for these families was moderate to high. Nonetheless, it is not known what the disclosure patterns would be in those families who refused to participate. Replication of the research with a larger sample would increase the validity and allow wider generalisation of the results. In addition, since practices surrounding embryo donation, and its prevalence may differ internationally, cross-cultural comparisons would provide useful information. The study is also limited by presenting the views of mothers only. Fathers may have different feelings on this issue, since previous research shows that couples in gamete donation families can hold dissimilar opinions regarding disclosure (Klock & Greenfeld, 2004). Although data was collected from fathers, it was felt that to discuss fully the issue of fathers' attitudes and inter-couple discrepancies would require empirical and theoretical investigation beyond the scope of the current paper, and therefore would be better presented separately in a future article. Despite these limitations, the study represents the first investigation of its kind to provide important preliminary findings on embryo donation families in the UK.

Concerns that non-disclosure will cause difficulties do not seem to be borne out at this stage, since the families were found to be functioning well in terms of parent-child relationships and child adjustment (MacCallum et al., 2007). Although parallels have been drawn between embryo donation and adoption, it is possible that the differences that exist between the two situations mean that disclosure is more necessary in adoption. However, the embryo donation children were very young so the possibility remains that problems will develop as they grow older, and perhaps become aware that there is a secret in the family, or indeed find out about the donor conception. A follow-up study is currently being conducted to investigate this issue.

It is also worth noting that the concerns voiced by the non-disclosing parents may not be valid. A study of a small number of donor insemination parents who had told their child about their conception reported that, rather than being distressed by this information, the children generally reacted with either curiosity or disinterest (Lycett et al., 2005). Similarly, studies in New Zealand (Rumball and Adair, 1999) and in the US (Scheib et al., 2003) found that children conceived by donor insemination largely responded either positively or neutrally upon learning about their conception. This contrasts sharply with the negative consequences seen for donor offspring who learnt the facts later in life (Turner and Coyle, 2000), supporting the notion that if disclosure is to occur, the process is best begun at a young age and approached by parents in an age-appropriate manner. Presenting this more positive view of disclosure to donor conception parents may encourage more to initiate this process themselves, avoiding the risks of inadvertent disclosure with its potentially detrimental effects for the child and for family relationships (McGee et al., 2001).

The views of the embryo donation parents in the present study demonstrate a marked discrepancy from the advice given by the UK regulatory body, the HFEA, which states in its literature for parents that “It is certainly best to be open with your child/children about the circumstances of their conception. Secrecy on this subject isn't in their interests” (HFEA, 2007). If the aim of the HFEA is to reach the stage of adoptive families, where the overwhelming majority of parents are open with their children about the adoption from a young age, there is some way to go. Adoptive parents are educated about disclosure by social workers as part of the adoption preparation process, in addition to which they have access to post-adoption support services, and disclosure aids such as the child’s life-story book and materials explaining adoption in child-friendly terms. Similar information and support could be

made available for embryo donation couples. Useful resources to support the disclosure process are being produced, such as the "Telling and Talking" booklets published by Donor Conception Network (2006), but awareness of such materials is generally not high. Moreover, currently in the UK, couples can receive counselling if they wish through their fertility clinic during treatment, but as mental health professionals, counsellors should attempt to maintain neutrality on the issue of disclosure in order to protect the therapeutic relationship and allow the couple to come to a decision independently (Klock and Greenfeld, 2004). Thus, there may be a place for the establishment of post-treatment services specifically for couples who actively seek advice on when and how to tell the child after the birth. Parents should not feel forced into disclosure but should be equipped with all the available information in order to make the decision that best suits their family.

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